THE LONG-TERM CARE OMBUDSMAN PROGRAM: RETHINKING AND RETOOLING FOR THE FUTURE

Proceedings and Recommendations

APRIL 2003

National Association of State Long-Term Care Ombudsman Programs

The National Association of State Long-Term Care Ombudsman Programs (NASOP) was formed in 1985 and is a nonprofit organization. It is a membership organization made up of 52 state/territory long-term care ombudsman programs. NASOP is dedicated to improving the quality of life and quality of care of long-term care consumers through effective state long-term care ombudsman programs.

NASOP does this by:

- Holding national education and advocacy training conferences;
- Providing mentors for new ombudsmen;
- Bringing ombudsmen together to exchange information and develop strategies to better serve long-term care residents;
- Developing position papers on long-term care issues;
- Analyzing and commenting on national legislation, regulations, and policies that affect long-term care; and
- Working in conjunction with other organizations to advocate for and make changes that will improve the lives of long-term care residents.

For more information contact:

NASOP
2007 Trail Wood Circle
Midland, MI 48642-3787
Phone: 989-631-3817

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NASOP RETREAT

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Peachtree City, GA

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Carol Scott
President, NASOP, and
Missouri State Long-Term Care Ombudsman

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Foreword

The National Association of State Long-Term Care Ombudsman Programs (NASOP) is proud to publish the proceedings and background materials from our retreat: *The Long-Term Care Ombudsman Program: Rethinking and Retooling for the Future*.

The long-term care ombudsman program has now moved into its fourth decade and faces many challenges, including the aging of the baby boom generation, competition for resources, and a changing long-term care system.

Although the ombudsman concept has been in existence for hundreds of years, it is easily argued that the long-term care ombudsman program is the largest ombudsman program to date. Given its size and longevity, it has received relatively little attention, inadequate resources, and little research or scrutiny. As the members of NASOP look toward the new millennium, we embrace the notion of evaluation and critique from those inside and outside the program.

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The questions and issues were numerous, but the mission was to evaluate whether the program is living up to the hopes of its creator, Arthur Fleming, former Commissioner on Aging and the first Secretary of Health, Education, and Welfare. He envisioned making justice and human dignity a reality for all individuals who reside in long-term care facilities. NASOP believes that in order to be viable, the ombudsman program must change as needed and remain contemporary. We must respond to the needs of long-term care residents by rethinking and retooling for the future.

We chose to face these challenges head on with the help of many of our colleagues at our retreat last year. We hope that you will see from this report that NASOP, with help from the Helen Bader Foundation, has carefully looked at the past, analyzed the current challenges, and begun a proactive and thoughtful agenda through the recommendations of the retreat. Our goal is simply to strive for excellence in the ombudsman program to ensure a better quality of life for millions of long-term care residents across America.

Carol Scott
President
NASOP

Executive Summary

In 2001, the National Association of State Ombudsman Programs (NASOP), a non-profit organization composed of state long-term care ombudsman programs, received a grant from the Helen Bader Foundation to convene a forward-looking conference with a unique format. The retreat became an all-encompassing review of the ombudsman past, reflection on the present program, and consideration of its future. The format, which included commissioned white papers and a series of consensus-building sessions, involved all of the retreat participants in debates and discussions to a degree not commonly seen at a conference. The result was a series of recommendations in six key areas that will help state and local long-term care ombudsmen shape their programs in the years to come.

NASOP set out a number of ambitious goals for the retreat. It wanted a comprehensive review of the current research and knowledge about the long-term care ombudsman program (LTCOP), the characteristics of the long-term care population it serves, and the changing health care climate of the 21st century. It wanted to educate and inform the participants on these topics as well as stimulate discussion around the more controversial issues. Another goal was to consider how better to coordinate services for people with Alzheimer's disease and their families. NASOP also wanted to develop materials that could be used in publications, testimony, speeches, and other public commentary on the program and long-term care in general. Improvement in the ombudsman program and in the care of long-term care residents was the ultimate goal.

In order to accomplish these goals, NASOP asked the Retreat Advisory Committee to bring together a multidisciplinary group of individuals from the aging network, local and state ombudsmen, researchers, health care professionals, residents and their families, state and federal officials, and representatives of the health care and long-term care industries. The committee also commissioned six leading health and aging scholars and policy experts to prepare white papers for the retreat. The papers were sent to the retreat participants in advance of the weekend retreat so they would be fully prepared for the discussions and deliberations.

The Retreat Advisory Committee developed a consensus building format which involved small breakout groups, meetings of consensus committees, and then discussions and conclusions at the plenary session with the full body of participants. The recommendations evolved throughout the series of meetings – not all of the recommendations were accepted at each meeting and some were modified at each step. The result was 46 recommendations supported by the full body of participants.

The retreat evaluations showed that the participants came away with a sense of having accomplished a great deal. In addition to sharing information and expressing ideas, the participants were able to explore their visions of the improvements and successes they wanted to work toward in the coming years. The ombudsmen particularly felt a renewed sense of mission about their work. The NASOP retreat gave

the participants, the organization, and the field of long-term care some new tools and resources for shaping the LTCOP's future, not the least of which is the resolve to meet obstacles and overcome challenges for the benefit of the long-term care ombudsman program and the population it serves.

NASOP will continue to use the materials created for the retreat and its outcomes to shape NASOP's strategies for the future of the ombudsman program.

Overview of Topics and Recommendations Developed at the Retreat

Independence

The ability of the ombudsman program to carry out its responsibilities rests to a large extent on the degree of independence, or program autonomy, the ombudsman experiences. Two major factors that affect ombudsman independence are the organizational placement of the program and actual and perceived conflicts of interest. Other critical factors influencing independence include the degree to which ombudsman programs control their program resources, including budgets and expenditures, as well as the extent to which the program is accountable to residents and the public. Research by Carroll Estes found that program effectiveness is linked to the independence of the ombudsman program.

The retreat participants developed recommendations in several key areas that address independence. One set of recommendations lists in detail potential conflicts of interest and whether the conflicts should be eliminated or merely managed. This is an important concession to necessity, as the retreat participants felt strongly that an ombudsman's credibility rests, in part, on her or his being free of real or apparent conflicts of interest.

Another key area in the Independence section involves the Administration on Aging. In several recommendations, the retreat participants call on AoA to support the ombudsman quest for program autonomy. The LTCOP needs AoA to review and eliminate conflicts of interest, to monitor Older Americans Act (OAA) compliance, and to provide the ombudsmen with a full-time national-level administrator. The participants noted that AoA should receive the resources necessary to allow it to comply with the responsibilities required by the OAA.

Systems Advocacy

The retreat participants agreed that nationally, the long-term care ombudsman program is not consistently fulfilling its mandate to pursue systems advocacy. The participants found that barriers to systems advocacy included insufficient ombudsman education and training, lack of monitoring and enforcement on the state and national level, and inadequate partnering with other appropriate organizations.

Therefore, the recommendations for the topic of systems advocacy focused on training, support, relationships with other organizations, and accountability.

There were three recommendations of particular interest that emerged from the consensus building process. One recommendation calls for conducting oral interviews with state and local ombudsmen to get a full sense of the barriers, attitudes, and approaches to systems advocacy. Another was the belief on the part of the retreat participants that they must police themselves; therefore they recommended that NASOP develop intervention strategies and remedies for programs and states that are not doing a good job of systems advocacy. A third area of importance was a set of recommendations proposing better communication and closer working relationships with the National Association of State Units on Aging (NASUA), the National Association of Area Agencies

on Aging (N4A), state units and area agencies on aging, as well as the National Association of Legal Services Directors (NALSD), and the National Association of Adult Protective Services Administrators (NAAPSA). It was felt that these organizations have a role in peer education and support of the ombudsman goal of systems advocacy. They also share the ombudsman and NASOP goal of serving older people and improving the long-term care resident's quality of life.

Training and Qualifications

The role of the ombudsman in the long-term care setting is demanding, requiring a wide range of abilities, knowledge, and characteristics. The environment may be unfriendly or even hostile, the residents are typically frail and may suffer from Alzheimer's disease or have other limitations to communication, and the ombudsman works alone. Clearly, an ombudsman must be well trained to solve problems and pursue advocacy in a variety of settings and situations.

By the same token, recruitment strategies and techniques must identify appropriate candidates for the job — paid or volunteer — in terms of skills, values, and temperament, so as not to waste personal or program time and resources. Turnover among ombudsmen, including volunteers, can be exacerbated by inadequate selection procedures and insufficient training, supervision, and support. The consequence of insufficient training and high turnover rates is that LTCOP effectiveness can be compromised, resulting in lost opportunities for advocacy, unsolved or inadequately solved problems, unmet needs, and dissatisfied clients.

The retreat participants were well aware of the challenges facing ombudsmen. The recommendations are appropriately sweeping as well as detailed. The first recommendation suggests the development of a mission statement because training should emanate from the values articulated in such a statement. The primary recommendation of the Training section calls for national training standards developed by a task force consisting of NASOP, the National Association of Local Long-Term Care Ombudsmen (NALLTCO), the National Long-Term Care Ombudsman Resource Center (NORC), and others. It outlines what the standards would address, what the subjects for new and continuing education should be, and specifies various training methods, including on-line learning. Another key recommendation urges NASOP to develop hiring and management tools for use by state and local programs.

Data and Information

Ombudsmen know that data and information, if done well, not only tell the story of how their program works, but also paint an accurate picture of the circumstances in which residents of nursing homes, assisted living, and other residential facilities find themselves. While specific case examples or anecdotal stories illustrate the story and provide emotional context, data provide a more complete picture. Data give a story scope and impact, making it more difficult for bureaucrats, the media, the public, and policy-makers to dismiss individual cases as isolated or "merely anecdotal." Analysis of data can also assist long-term care ombudsmen in determining topics for training programs.

The recommendations for LTCOP Data and Information reflect three concurrent needs. One is the need to educate program staff and volunteers on the usefulness of data and the importance of complete and reliable data collection, entry, and analysis. The second need for NASOP, in conjunction with AoA and NORC, is to plan and implement a restructured and improved national reporting system. The system would be able to

incorporate all kinds of data, from many sources, and be useful for comparisons, research, analysis, and education. The third area involves developing a funding strategy to obtain the necessary hardware and software for all LTCOPs to be technically and technologically up-to-date.

Program Effectiveness

The concept of program effectiveness incorporates all of the topics addressed at the NASOP retreat. Retreat participants know that effective advocacy is influenced by the organizational placement of the program and how much independence it has, the training and supervision of the staff and volunteers, the approach to systems advocacy, and the ability to measure and describe success and failure. Part of program effectiveness is dependent on the ombudsman's understanding of the special needs of the long-term care population, the changing nature of the long-term care industry, and knowing current research and best practices.

The recommendations that evolved from the discussions and debates at the retreat focused more specifically on the program operation aspect of program effectiveness. Two of the recommendations relate to the direction, supervision, and monitoring that those who are accountable should provide: from the director of the Office of Long-Term Care Ombudsman Programs in AoA, to the state long-term care ombudsman. Two of the recommendations are specifically prescriptive: one about the proper staffing equivalents and one about the response time for complaints of various priority levels. One recommendation addressed the issue of program placement and structure in order to maximize independence and minimize conflict of interest.

One of the most important recommendations challenged NASOP, NORC, and NALLTCO to develop a tool to measure ombudsman program effectiveness. The ability to evaluate a program's effectiveness has far-reaching implications for the program's future success.

The Changing Long-Term Care Resident Population and its Needs

The author of the white paper on this topic discusses the changes that have taken place in the long-term care field since the long-term care ombudsman program began three decades ago. Paramount is the growth of the elderly population, especially the oldest old and individuals suffering from Alzheimer's disease. This population growth has had an impact on long-term care and, by association, the long-term care ombudsman program. In addition, the long-term care resident no longer resides only in traditional nursing homes. Board and care facilities, assisted living facilities, and community and home based care are common settings for people in need of ombudsman services.

The Changing Population recommendations address a broad range of issues. One of the recommendations suggests independent research to determine the actual cost of the ombudsman program if all of the OAA mandates were fulfilled. Another recommendation urges NASOP to continue its work on national standards of care for assisted living. Training programs for long-term care ombudsmen on Alzheimer's disease, dementia, depression, and delirium are the focus of another recommendation. All of these recommendations are unique and urgent.

This topic contains the only recommendation from the retreat that deals with the LTCOP's public image. It calls upon NASOP to work with other organizations to develop a public awareness campaign to heighten the visibility of the LTCOP and the people it serves.

Introduction

The world of long-term care has changed dramatically since 1971 when the Long-Term Care Ombudsman Program was created. In addition to the growth in the older population, there have been changes in the financial status of the long-term care industry and in the way care is delivered in various settings, including nursing homes, board and care, assisted living, home care, managed care, and other settings. Advances in health care technology, more acutely ill patients, and the growing medicalization and professionalism of community care affect the treatment that long-term care residents receive and the demand for advocacy programs like the long-term care ombudsman program.

The Institute of Medicine conducted a yearlong study of the long-term care ombudsman program in 1995, *Real People Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*. The IoM concluded that the ombudsman program serves a vital public purpose and contributes uniquely to the well being of long-term care residents and their families. It supported the program's mandate and its continuation. Further, the IoM report found that the program was not adequately funded and made several recommendations intended to build the program and bring it into compliance with law. It also acknowledged the program as a potential model for other health care ombudsman programs.

In order to remain responsive to its constituency, many in the long-term care ombudsman program believe that it must periodically review its mandate, assess its effectiveness, and closely examine the changing face of the population it serves. For example, most ombudsmen now regularly encounter people with Alzheimer's disease on their facility visits. Up to one-third of nursing home residents may have Alzheimer's disease. Ombudsmen need to be trained regarding the best advocacy services that will benefit individuals with Alzheimer's disease and their families. In addition, there is a need to reassess the research of the past and its recommendations and relevance to the long-term care system of the future.

To this end, the National Association of State Long-Term Care Ombudsman Programs (NASOP) received a generous grant from the Helen Bader Foundation to address these programmatic challenges. In February 2002, NASOP convened a consensus-building conference, *The Long-Term Care Ombudsman: Rethinking and Retooling for the Future*. The goal was to assemble a unique and diverse group of leaders to examine the past, present, and future of the long-term care ombudsman program, and to build consensus on recommendations for the next decade. Sixty-five individuals participated in the retreat.

The Retreat Advisory Committee chose policy paper topics and authors for the papers and helped select invitees. Moreover, the committee determined that a consensus format, while unique, was an excellent way to intimately involve many ombudsmen, health care and aging experts, and other advocates and stakeholders in a dialogue that would invest and invigorate them for the work that lies ahead.

The policy and technical papers were commissioned to inform the retreat participants of the most current analyses of issues regarding the program, the changing long-term care environment, and options for the program's future. The six topic areas were:

- Independence of the ombudsman
- Systems advocacy in the ombudsman program
- Training and qualifications of the long-term care ombudsman
- Program data and information collection, analysis, and dissemination
- Program effectiveness
- Changing population and needs of the long-term care resident

These topics are the critical issues that have manifested themselves over the past years in the ombudsman program. Their interconnectedness is exemplified by the fact that a number of the papers address issues that bear on the program's effectiveness, itself a paper topic.

The papers were distributed to the participants prior to the retreat for review. The papers were designed to form the basis for discussion and recommendations. When possible, the paper authors presented their own papers to the participants. Each paper had a track at the retreat. Each track was divided into two breakout groups so that smaller groups could work concurrently to discuss the issues, propose recommendations, and develop consensus. Facilitators were delegated to stimulate response and discussion in each track's session and recorders were used to take notes and record consensus decisions. Each breakout group sent representatives to meet in smaller settings called conference committee meetings. The conference committees reported a set of no more than ten recommendations for each paper topic to the full body at a plenary session. During the plenary session, the full group discussed, modified, and developed consensus around recommendations in each topic area. Detailed descriptions of the consensus building process, the groups' discussions, and the recommendations are featured in this report.

The retreat participants were fortunate to hear from two very special speakers: Ms. Martha Eaves and Ms. Jean Scher. They provided the perspective of witnesses to the changes in the ombudsman program over the years and of personal contact with the program. Ms. Eaves has followed the program through her work as the Chair of the Georgia Council on Aging and as an advocate. Ms. Scher spoke to the group as a former nursing home resident and family member of a nursing home resident. Their real life lessons in advocacy helped to frame the retreat and inspire its participants.

NASOP would like to thank the Helen Bader Foundation for its support of the retreat, especially Robin Mayrl of the Helen Bader Foundation for her guidance and encouragement. Also, NASOP thanks the members of the Retreat Advisory Committee, and the retreat participants themselves, for making the retreat a success.

NASOP would also like to acknowledge and thank the talented paper authors: Carroll L. Estes, Robyn Grant, Elma L. Holder, Esther Houser, James R. Kautz, and H. Wayne Nelson, Jr. The complete texts of the papers can be found in the Appendices to this report. The National Long-Term Care Ombudsman Resource Center (NORC), directed by Alice Hedt, was extremely helpful to the authors and staff of the retreat.

NASOP would also like to recognize the hard work of the facilitators and recorders as well as Pam Carlson and the other staff of Management Plus for their logistical contributions. NASOP is grateful to the staff that conducted the bulk of the work that a

project of this magnitude requires: Bill Benson, Kate Hughes, Sara Hunt, and Brian Lindberg. Special appreciation goes to Bill Benson, who ably served as the facilitator for the plenary sessions.

Finally, NASOP is indebted to George Potaracke and Brian Lindberg for having the vision for this endeavor and securing the resources to make it happen.

NASOP will continue to use the materials created for the retreat and the discussions and recommendations of the retreat itself to shape its strategies for the future of the ombudsman program. This manifests itself in programs, publications, testimony, speeches, and other public commentary on the program and long-term care in general. Improvement in the ombudsman program and in the care of long-term care residents is the ultimate goal.

Overview of Paper Topics and Authors

NASOP commissioned papers on six priority topics for exclusive use at the retreat. Leading scholars and experts in the field of aging, ombudsman programs, and long-term care policy wrote the papers. The authors were asked to provide an overview of the current situation, background information as necessary, the most up-to-date research findings, and analysis and recommendations. The retreat participants received the papers in advance so that they could attend ready to discuss, debate, and build consensus on the recommendations. Retreat participants were informed that the authors' views were not necessarily those of NASOP.

Independence: The Long-Term Care Ombudsman Program's Ability to Fully Represent Residents, by Carroll L. Estes, Ph.D.

Dr. Estes is a Professor of Sociology at the University of California, San Francisco. She is a leader in the field of aging, long-term care, and health policy and one of the nation's foremost scholars of gerontology. She is the author of 6 books and more than 100 scientific articles and book chapters. Dr. Estes chaired the 1995 IoM study on the LTCOP. She has been honored with numerous awards for her accomplishments in research, policy making, and education. In 1998, the League of Women Voters named her "A Woman Who Could Be President."

Dr. Estes's paper on independence focuses on the ability of the ombudsman to fully represent the residents of long-term care facilities given the program's mandate and structure under the Older American's Act. During 2000 and 2001, Dr. Estes and colleagues at the Institute for Health and Aging, University of California, San Francisco, conducted a study of state LTCOPs. The researchers found that organizational placement, conflicts of interest, and fiscal control are some of the key elements affecting the ombudsman program's independence. Further, they found that lack of independence or inadequate program autonomy inhibits the effectiveness of the ombudsman program. Dr. Estes provides research findings, analysis, and suggestions for securing program independence and improving program effectiveness.

Systems Advocacy and the Long-Term Care Ombudsman Program, by Esther Houser, M.S.W.

Ms. Houser has served as the State Long-Term Care Ombudsman in the Aging Services Division of the Oklahoma Department of Human Services since 1979. Her area of expertise includes ombudsman practice and long-term care issues, and she has published numerous articles and manuals on these topics. Ms. Houser served two terms as President of NASOP.

Ms. Houser's paper on systems advocacy describes the broad range of advocacy activities that long-term care ombudsmen conduct. While the Older Americans Act has been strengthened over the years to support advocacy work of the ombudsman

program, Ms. Houser describes how in some cases states still prevent the long-term care ombudsman program from carrying out its full range of systemic advocacy. The mission of the long-term care ombudsman is to represent the interests of long-term care residents, not the state, providers, or even the aging network. As a result, Ms. Houser points out, the vulnerability of the program is obvious. The federal government bears the responsibility to evaluate each state's performance related to the program and to enforce the OAA. Ms. Houser's paper includes several recommendations on improving the ombudsman's ability to advocate effectively, from evaluation of performance and practical training of state and local ombudsmen, to action on the legislative and national level.

Training and Qualifications for the Long-Term Care Ombudsman Program, by H. Wayne Nelson, Jr., Ph.D.

Dr. Nelson is an Assistant Professor in the Department of Health Science at Towson University, MD. He has more than 15 years of experience overseeing Oregon's long-term care system as the Deputy Director of Oregon's state long-term care ombudsman program. Dr. Nelson is a Summer Fellow for the National Institute on Aging, Summer Institute on Aging Research. His academic and professional experience combines theory and practice on aging, advocacy, the ombudsman program, and other aspects of long-term care administration. In addition to publishing numerous articles, Dr. Nelson has served on many state and national task forces, provided training to ombudsman programs, and has been a spokesman in the media and to policy makers on aging issues.

Dr. Nelson's paper addresses the challenges of training and certification in the long-term care ombudsman program. To develop a "standard of best practice," Dr. Nelson points out that a number of concepts, subjects, and issues must be pulled together into a cohesive approach to training, educating, and evaluating ombudsmen. This paper discusses the differences between paid and volunteer ombudsmen, conflicts of interest, inconsistent training, the need for certification exams, the importance of continuing education, the role of performance reviews, and other areas critical to establishing consistently effective long-term care ombudsman programs. Dr. Nelson offers detailed recommendations for addressing the problems in ombudsman program training.

Long-Term Care Ombudsman Program Data and Information, by James R. Kautz, Ph.D.

Dr. Kautz recently completed a 21-year career in state government. In addition to experience in corrections, hospitals, and aging services, Dr. Kautz has served as a state long-term care ombudsman and a state unit on aging director from 1985-1990. His areas of expertise include program performance measures and quality of services. He has worked with NASOP and NASUA, and contributed a paper to the Institute of Medicine's study of ombudsman programs.

Dr. Kautz's paper describes how the use of data has become a valuable tool for many ombudsman programs. Statistics now provide support for advocacy positions, form the basis for priorities, and provide rationales for training programs. The proper use of data also helps ombudsmen inform individuals, legislators, and the media about issues such as quality of care. With the increase in the use and importance of data come problems with its collection and dissemination. Dr. Kautz points out that computerization has raised new issues about confidentiality of records as well as the adequacy of the computer systems themselves. The author describes the features of a useful data system and

discusses ways that the Administration on Aging and national and state agencies can facilitate improvement in data and information use by long-term care ombudsman programs.

Long-Term Care Ombudsman Program Effectiveness: Building Strong Advocacy, by Robyn Grant, M.S.W.

Ms. Grant is a consultant with the National Long-Term Care Ombudsman Resource Center and the Manager of Advocacy Services with an elder law firm in Indianapolis. Ms. Grant served as the Indiana State Long-Term Care Ombudsman for eight years. She has also served two terms as President of NASOP and is currently on the boards of the United Senior Action Foundation and the National Citizens' Coalition for Nursing Home Reform.

Ms. Grant approaches the discussion of program effectiveness by describing an effective ombudsman program as one that pursues individual advocacy (individual resident issues) and systems advocacy (representing the interests of residents in general). She then defines the elements of an effective program, from its accountability and its goals and priorities, to its infrastructure and operation. For example, Ms. Grant points out that the organizational placement of the program must be unencumbered and free of conflicts of interest. She also discusses the financial resources required to support an effective long-term care ombudsman program, as well as the influence of relationships with other agencies, programs, and groups. Recommendations are offered for improving each element of program effectiveness.

The Changing Long-Term Care Resident Population and Its Needs, by Elma Holder, M.S.P.H.

Elma Holder founded the National Citizens' Coalition for Nursing Home Reform and served as the organization's executive director from 1975-1995. Prior to that role, Ms. Holder worked as a gerontology and health consultant for state and national agencies. Ms. Holder has received numerous awards for her groundbreaking work serving nursing home residents and improving nursing home care. Among those honoring her have been the Consumer Federation of America with the Esther Peterson Advocacy Award, Allied Signal with the Achievement Award in Aging, the Health Care Financing Administration (now "CMS") with the Administrator's Award, and the National Academy of Sciences with the Institute of Medicine "Gustave Leinhard" award. In 1998, *Contemporary Long Term Care*, a nursing home industry trade magazine, named Ms. Holder one of "20 Who Make a Difference."

Ms. Holder's paper describes how the composition of the long-term care population has changed over the years. Long-term care residents are likely to be older, with greater health care needs, especially those with Alzheimer's disease and other dementias. There is more diversity among the residents. Veterans and various ethnic and cultural groups are often underserved and need special assistance. People with disabilities who live in the community need specialized advocates to help them maintain their quality of life. Managed care presents new complexities and problems for consumers. Ms. Holder shows how these and other factors have a tremendous impact on long-term care facilities and on the ombudsman program. She enumerates the considerations that must be addressed when program expansion is discussed, as well as suggests how the ombudsman program can better serve a diverse population of home- and community-based long-term care clients.

Retreat Design: The Consensus Building Process

The goal of this retreat was to arrive at a set of conclusions and recommendations that would help steer the course of state long-term care ombudsman programs. The Retreat Advisory Committee designed the retreat specifically to ensure that the conclusions and recommendations reached would be based on the consensus of the participants. The retreat design included the following elements:

- Commissioned white papers written by leaders in the field of aging and ombudsman programs
- Discussion questions at the end of each paper
- Breakout groups corresponding to each paper topic
- Facilitators and recorders in each breakout group
- Conference committee meetings to select and prioritize recommendations from the breakout groups
- Plenary sessions.

Each conferee participated in two different breakout sessions on different topics. The breakout sessions corresponded to the six papers each participant received prior to the retreat: Independence, Systems Advocacy, Training and Qualifications, Data and Information, Program Effectiveness, and Resident Population. There were two breakout sessions offered at different times for each of the six topics.

Each breakout group was asked to reach agreement on five to ten specific recommendations directly relevant to its assigned topic. Discussion questions were provided. The exact process used for reaching consensus on the recommendations was left to each breakout group. Groups typically chose to discuss key topics from the papers, modify or draft recommendations, and take a poll of those who supported the recommendations. The authors of the topic papers participated and served as sources of information and analysis. Each breakout session had a facilitator who helped move the discussion toward consensus on the different recommendations and conclusions. A recorder captured the discussions. The breakout sessions lasted two hours and fifteen minutes with approximately ten people in each group.

Since there were two breakout groups addressing each of the topics, the retreat planners knew that the groups might arrive at different or even conflicting recommendations. Therefore, a process for reconciling differences or compromising on differences was included in the retreat design. These “conference committee” meetings were held between representatives of each of the breakout groups to reach agreement on the recommendations that would be presented in the plenary sessions. For example, representatives of the two breakout groups addressing “Independence” met in a “conference” session to decide which recommendations to offer on behalf of

the two “Independence” groups and which would be the priority recommendations. Ninety minutes were available for the conferencing process. Conference committees were asked to bring no more than ten recommendations to the full group.

Two plenary sessions were held to discuss and consider each of the recommendations developed during the conference meetings. The conference meeting representatives presented their recommendations for up to 15 minutes, with 45 minutes for discussion and reaching consensus among the full body. A total of six hours was dedicated to this part of the process (one hour per topic). The first plenary session considered three retreat topics (Independence, Systems Advocacy, and Training and Qualifications) and the second addressed the remaining three topics (Data and Information, Program Effectiveness, and the Changing Resident Population).

The consensus building process during the plenary session did *not* include vote taking or prioritizing recommendations. However, the facilitators attempted to come to an understanding of where the full group of retreat participants stood on the recommendations and issues. For example, the facilitators considered whether the participants gave the recommendation: 1) strong support – “a thumbs up,” 2) moderate support – “it isn’t perfect, but I can live with it,” or 3) little support – “this is unacceptable.”

When the consensus building process was completed for the six topics, the full body discussed implementation strategies for the recommendations, as time allowed.

All of the work at each stage of this consensus building process was important to the success of the retreat and the sharing of ideas and information with NASOP.

Independence: The LTCOP's Ability To Fully Represent Residents

Retreat Recommendations and Analysis

The ability of long-term care ombudsmen to fulfill the promise to long-term care facility residents and the public, as contained in the Older Americans Act rests, to a large degree, on the independence of the individual ombudsman and program. A host of factors can influence the extent to which an ombudsman can perform her or his duties freely and fully – that is, without constraint. Two major factors that can have a profound effect on ombudsman independence are the organizational placement of the program and actual and perceived conflicts of interest. If the organizational location of the LTCOP is such that there are impediments to the ombudsman freely representing the needs and interests of residents, then the ability of the LTCOP to serve as an independent voice and advocate for residents is impaired if not destroyed. The impediment may be because the ombudsman is constrained from representing residents without the approval – explicit or implicit — of his or her superiors, or because the organization engages in activities that conflict with or are perceived as conflicting with the ombudsman's role. Ombudsmen may face impediments within their own organizations by restraints placed upon them by their superiors. Such restraints may include limiting or prohibiting ombudsmen from directly participating in activities that address policy matters related to residents and LTC facilities (e.g., committees, meetings, providing information).

Other critical factors influencing independence include the degree to which ombudsman programs control their program resources including budgets and expenditures, as well as the extent to which the program is accountable to residents and the public.

Carroll L. Estes conducted research to examine the LTCOP with particular emphasis on issues related to the program's effectiveness, independence, and its ability to engage in systemic advocacy. Selected results from Dr. Estes's research are found in the paper that she prepared for the retreat (see Appendix IV of this report). Dr. Estes found that more than half of the state long-term care ombudsmen (55%) stated that the organizational placement of their program creates difficulties for fulfilling their OAA responsibilities. Reported difficulties included "lack of autonomy to speak to legislators or the media, conflicts of interest, bureaucracy, limited access to resources; and budget vulnerability" (Appendix IV, Estes, p. 4). LTCOPs located within state agencies (both SUA and non-SUA) are much more likely (63% and 60%, respectively) than state LTCOPs located within legal services offices or nonprofit agencies (22%) to report difficulties in carrying out their responsibilities and providing services to facility residents (Appendix IV, Estes, p.4).

In her paper, Dr. Estes emphasizes that the extent of reported program autonomy is statistically significantly associated with state ombudsmen being able to carry out

successfully their federally mandated duties on behalf of long-term care residents (Appendix IV, Estes, p. 7).

The retreat included specific discussion about whether the LTCOP could function effectively located in an entity of government, including state units on aging. Although there was not unanimous agreement on this issue, retreat participants did not recommend or intend to imply that LTCOPs should be moved outside of government.

Conflict of Interest

1.1) A LTCOP located in an entity of government (state or local) or agency outside government whose head is responsible for the following faces potential conflicts of interest that must be prohibited:

- **Licensure, certification, registration, or accreditation of long term care residential facilities;**
- **Provision of long-term care services, including Medicaid waiver programs;***
- **Long-term care case management; ***
- **Reimbursement rate setting for long-term care services;**
- **Adult protective services; ***
- **Medicaid eligibility determination;**
- **Preadmission screening for long-term care residential placements;**
- **Decisions regarding admission of elderly individuals to residential facilities (Harris-Wehling, Feasley & Estes, 1995; Recommendation 4.1, pg. 124);**
- **Guardianship services;**
- **Management or ownership of a long-term care facility.**

**** Conflict of interest may be managed rather than prohibited***

Both breakout groups included this recommendation in their proposed recommendations. Concerns about actual and perceived conflicts of interest are especially significant for ombudsmen; hence the detailed list of situations where conflicts tend to arise. Participants recognize that the ombudsman's "stock-in-trade" is his or her credibility or word. Since ombudsmen have no enforcement power, they can neither compel action by any parties nor sanction them for failure to act in some way. The ombudsman's only power is the power to convince others to "do right" for the complainant or residents in general. Thus, it is imperative that the ombudsman and the program be perceived as free of conflicts of interest.

The conference committee discussed whether management of a conflict of interest is sufficient rather than to require a strict prohibition on every form of potential conflict of interest, and agreed that in some cases it is. Nevertheless, the overall feeling of the participants was that it is preferable to prohibit rather than manage conflicts of interest. Yet, there was clear recognition among the participants that this may not always be possible or may be too difficult to implement in some circumstances.

1.2) States must identify and propose remedies to conflicts of interest and report to the Administration on Aging. The AoA Office of Long-Term Care

Ombudsman Programs should review, for the purpose of approval or disapproval, states' proposed remedies to conflicts of interest.

1.3) In collaboration with stakeholders, AoA's Office of Long-Term Care Ombudsman Programs must identify conflicts that must be eliminated.

These recommendations reflect in large part the desire of participants that AoA play a more active role in oversight, guidance, and monitoring of the LTCOP. Not only is this perceived as an appropriate role for the federal agency responsible for overseeing the OAA on a national basis, but is also consistent with AoA's statutorily based advocacy role. The organizational placement of individual LTCOPs, and the circumstances under which they operate, may well require that AoA perform its oversight responsibilities to rectify situations involving actual or perceived conflicts of interest, and to ensure that older Americans and their families receive the assistance of ombudsmen that best reflects the letter and spirit of the OAA.

Independence and Authority

1.4) LTCOP autonomy is essential to program effectiveness. State LTCOPs should have sufficient organizational autonomy from the state to ensure that ombudsmen may advocate for residents (in accord with their responsibilities as defined by law) without fear of political ramifications. As advised by the 1995 IoM Report: "Ombudsmen must be able to pursue independently all reasonable courses of action that are in the best interest of residents."(Harris-Wehling, Feasley & Estes, 1995; pg. 125). Therefore, NASOP should work to ensure that in order to comply with the Older Americans Act, Section 201, the Administration on Aging should include a position responsible for the administration of the ombudsman program. A full-time dedicated position (Director of the Office of the Long-Term Care Ombudsman Programs) should report directly to the Assistant Secretary on Aging.

The conference committee reached consensus on this recommendation, but no consensus was reached during the plenary session. While there is a clear sense among ombudsmen that the position of Director of the Office of LTCOPs at AoA should be full-time, there is recognition that even a part-time position is desirable in the absence of a full-time position. NASOP is grateful that the Assistant Secretary for Aging has named a senior staff member to serve as Director of this office despite the fact that the incumbent has many other demanding responsibilities within AoA. Nonetheless, NASOP believes that a part-time position is a positive step forward.

The following language was deleted during the final discussions: *The ombudsman position at the state and local levels should be elevated to report directly to the director of the respective agency (if the ombudsman is not the director), for the purposed of maximizing independence.* In part, this reflects participants' recognition that such a requirement would be exceptionally difficult and disruptive to the program in a number of states.

Accountability

1.5) The Administration on Aging should monitor the LTCOP compliance with the Older Americans Act. AoA's Office of Long-Term Care Ombudsman Programs

should be provided adequate resources to fulfill the responsibilities required by law.

This recommendation is similar to a recommendation that emerged from the Effectiveness group, reflecting the overall importance of this activity. The provision in Title II of the OAA requiring that the Administration on Aging establish an Office of State Long-Term Care Ombudsman Programs and that a "Director head it" was created for several key purposes. These include providing a focal point within the federal government for the states' LTCOPs, monitoring the overall effectiveness of LTCOPs, and responding to complaints and concerns that the individual states' LTCOPs are not in compliance with OAA provisions. The participants agreed that given the statutory array of roles and responsibilities delineated in the OAA for this position, it couldn't be effectively implemented without adequate resources.

1.6) Mechanisms should be developed to hold the program accountable to fulfill the public trust, including:

- **Ensuring that state long-term care ombudsman programs have their own independent advisory boards;**
- **Dealing with potential or actual conflicts of interest;**
- **Hearing disputes around program independence and autonomy and working to resolve them.**

Whereas the LTCOP endeavors to hold the various parties of long-term care accountable for the performance and behavior from the perspective of the wishes and needs of residents, the program must also be accountable as a matter of public trust, especially to long-term care facility residents and to the public. The retreat participants believe that achieving these recommendations would represent major steps in ensuring the LTCOP is indeed accountable for its work. Participants also believe that all stakeholders in the LTCOP especially AoA, the SUAs, state and local LTCOPs, and NASOP must be committed collectively and individually to fulfilling this recommendation.

1.7) Research and evaluation should be conducted on the issues of the autonomy and independence of the program including the organizational structure and placement of the LTCOP that will allow ombudsmen best to meet statutorily mandated requirements, including complaint investigation; resident, family, and community education; and systems level advocacy. Issues of conflicts of interest also need to be investigated.

Dr. Estes's recent research about the LTCOP has contributed a great deal of new knowledge and understanding regarding the extent of autonomy in long-term care ombudsman programs and the consequences of its presence or absence. This work, coupled with the landmark IoM study of the LTCOP, chaired by Dr. Estes, and limited research by others have been essential to improvements in the program. It is clear from the deliberations during the retreat that the participants and NASOP believe that continuing research and evaluation that examines the program at the national, state, and local levels is essential for the following: continuous improvement in the LTCOP; ensuring that, in every state, it fulfills the promises of the OAA and that all residents can expect a consistent level of service regardless of where they reside; and ensuring that the program adapts appropriately to the changing world of long-term care.

Systems Advocacy in the LTCOP

Retreat Recommendations and Analysis

Systems advocacy is central to the roles and purpose of the long-term care ombudsman program. The Older Americans Act has long been clear on the importance of systems advocacy by ombudsmen: that it is an integral part of the LTCOP. From its earliest days, the LTCOP's mandate has been to "recommend changes in the long-term care system which will benefit institutional residents as a class" (AoA Program Instruction, 1981) (Appendix V, Houser, p.3). From the program's inception, it has been recognized that to focus solely on responding to individual complaints by individual residents would mean not only that ombudsmen address the same or similar matter over and over, but also that much larger numbers of residents with a similar problem would not be helped if all matters were handled on a case-by-case basis. Not only would that undermine program efficiency, but time and resource limits would dictate that large numbers of individuals would not receive help.

Esther Houser, the author of the paper on systems advocacy, observes that the range of activities constituting systems advocacy is very broad. Such activities can be focused on a single facility, all the facilities owned by one large provider or an entire chain, the industry as a whole, or other elements of the long-term care system, such as the regulatory and reimbursement systems. The goal driving ombudsman advocacy on any level is improving the lives and circumstances of long-term care clients individually and collectively.

In order to engage in systems advocacy in a meaningful way, state and local long-term care ombudsmen must have the resources and the autonomy to communicate on behalf of residents to providers, regulators, lawmakers, the media, and others in a position to influence or create change in practice and policy. Despite the statutory underpinnings of and the need for systems advocacy, there remains wide variation among states in the ability of the LTCOP to engage in systems advocacy. Some states' LTCOPs do not engage in advocacy activities at all beyond helping individual residents resolve their individual complaints (Appendix V, Houser, p.4). Others work indirectly through state and local citizen advocacy groups. Some state programs are not allowed to contact directly the media or policymakers. Moreover, many ombudsmen are hampered in their work by lack of independence related to their organizational placement. Severe limits in funds and personnel will likely mean that ombudsmen may have only the wherewithal to respond to individuals and be unable to address matters on a more systemic basis.

Inattention to or deliberate constraints on the ability of ombudsmen to do systems advocacy has been compounded by the lack of performance evaluation related to systems advocacy and outcomes and the lack of oversight of states' LTCOPs. Reports by the Office of the Inspector General, the General Accounting Office, and the Institute

of Medicine have found that states need more guidance from the federal government in general and specifically with regard to systems advocacy (Appendix V, Houser, p.4).

2.1) NASOP should work on the following recommendations because nationally, the ombudsman program is not consistently fulfilling the federal mandate to pursue systems advocacy.

As the retreat participants deliberated about the potential for and realities among LTCOPs related to systems advocacy, a clear consensus emerged that LTCOPs, at both the state and local levels, face numerous impediments to their ability to carry out this fundamental and crucial part of their responsibility. In short, because this mandate under the OAA is simply not met in far too many programs, serious problems affecting residents go unresolved and in some cases are exacerbated. The consensus is that eliminating these impediments must be a high priority by all stakeholders in the LTCOP, from ombudsmen themselves to policy makers to all state and area agencies on aging. Participants offered examples of state and local LTCOPs that are able to conduct effectively systems advocacy without hindrance or other major constraints. Some of these examples could be considered as best practice scenarios that should be emulated in other states and localities.

The members of breakout group one noted that there are a number of reasons why systems advocacy is not being aggressively pursued throughout the nation. The lack of resources, the organizational placement of the programs, and the failure on the part of the ombudsman program itself to understand that systems advocacy is one of their central duties were discussed. Inadequate training and lack of monitoring were also pinpointed.

Breakout group two brought recommendation 2.1 to the conference committee meeting with the terminology, “the ombudsman program is not fulfilling the federal mandate to aggressively pursue systems advocacy.” It was accepted. During the plenary session with the full body of retreat participants in attendance, the word “aggressively” was deleted from the last phrase and “consistently” was inserted. The retreat participants felt that the word “consistently” portrayed the on-going and regular nature of the ombudsman’s duty to systems advocacy. The term “aggressively” was not necessary because of the already important nature of systems advocacy.

First Step:

2.2) NASOP, in cooperation with the National Association of Local Long-Term Care Ombudsmen should conduct confidential oral interviews with all state ombudsmen and some local ombudsman to get a full sense of attitudes, barriers, and supports to fulfilling the mandate for systems advocacy.

The participants noted that local ombudsmen are an integral part of the long-term care ombudsman program. To fail to elicit information from local ombudsmen would create an incomplete picture of the ombudsman experience for they are the very people who carry out the day-to-day duties of the ombudsman program. Systems advocacy at the local level may be quite different from the work the state ombudsmen might accomplish. Local ombudsmen would most likely concentrate more on local entities, media, and legislators than the state ombudsman. Gathering information from local ombudsmen would provide necessary evidence as to the barriers to advocacy,

the need for training, and other important information.

In addition, one cannot necessarily draw conclusions about a program in one state from information about a neighboring state. It is necessary to collect information from each state.

The question was raised as to whether Carroll Estes had surveyed local ombudsman in her recent research. Carroll commented that her paper did not cover local ombudsmen. Carroll noted that this portion of her research was the most problematic and needed to be addressed further.

In the conference committee meeting, participants requested that NALLTCO work with NASOP on the interviews. The group thought this was appropriate and helpful, as NALLTCO is the ideal organization to work with NASOP on this recommendation.

Training:

2.3) The National Long-Term Care Ombudsman Resource Center should ensure that orientation of all new state ombudsmen include training in systems advocacy.

NORC is responsible for developing many of the training tools that ombudsmen use, as mandated by the Older Americans Act. So much of long-term care policy is federally developed and nationally applied, such as standards for nursing homes, that for consistency and completeness, training on systems advocacy appropriately would come from NORC.

2.4) The National Long-Term Care Ombudsman Resource Center should develop ongoing systems advocacy training, including community organization skills, for all state and local long-term care ombudsman programs.

The retreat participants felt that community organization skills were particularly valuable for promoting systems advocacy. The elements of organizing residents and their family member councils, and getting to know local policy makers are brought together under community organization skills.

Ongoing training is also necessary in situations of evolving research and changing best practices, as well as when new personnel join the ombudsman program.

2.5) NASOP should establish teams of experts to offer on-site visits to educate their state counterparts and the state unit director on effective systems advocacy. NASOP should work with the National Association of Legal Services Directors, the National Association of Adult Protective Services Administrators, and others as appropriate and necessary.

This strategy was recommended because the retreat participants felt that experienced peers are the best people to convey the intricacies of systems advocacy. In addition to NALSD and NAAPSA members, the “experts” would include individuals from state units on aging, area agencies on aging, as well as ombudsman program staff and citizen activists. It became clear that the retreat participants felt that there was no cookie cutter approach to systems advocacy.

Support:

2.6) NASOP should develop intervention strategies and remedies to assist state LTCOPs to fulfill their mandate for systems advocacy. Strategies might include training, mentoring visits, letters of support from residents and citizen groups, and other state and national senior organizations. Remedies might include congressional inquires, requests for sanctions, writs of mandamus, or private lawsuits.

Retreat participants endorsed this recommendation because it conveys an important aspect of the long-term care ombudsman philosophy of always seeking to improve the ability to serve residents. The recommendation specifies strategies and remedies to address state and local programs that are not adequately providing systems advocacy. The retreat participants believe that, through NASOP, ombudsmen must take it upon themselves to monitor state and local long-term care ombudsman programs; in essence, ombudsmen must police themselves. This is a logical and appropriate extension of systems advocacy. If states are not doing what they should be doing, i.e., systems advocacy, the entire ombudsman program can be hurt. If systems advocacy is not consistently being pursued throughout the country, the LTCOP mandate is not being fulfilled.

Relation to other Organizations:

2.7) NASOP should continue the dialogue with conference participants and other organizations to develop a joint policy statement supporting enforcement of the OAA mandate for systems advocacy.

This recommendation reflects the importance of involving the many organizations and agencies that work closely with state and local ombudsmen in promoting more effective systems advocacy.

2.8) NASOP should contact the National Association of State Units on Aging and reconvene the joint work group to address areas of concern and collaboration.

The participants felt that NASUA is pivotal to supporting enforcement of the OAA mandate, statewide and nationally.

2.9) NASOP should ask the National Association of State Units on Aging, especially due to its role in the National Long-Term Care Ombudsman Resource Center, to work with NASOP to address the barriers to effective ombudsman programs that exist in some state units on aging.

NASUA has a unique role to play because it represents the state units on aging. SUAs have special insight and perhaps understanding why some of the barriers to systems advocacy have evolved. NASUA has the ability to help facilitate the kinds of exchange of information and promotion of best practices within the state units. NASUA is also in a position to motivate SUAs that have not performed well with systems advocacy.

2.10) NASOP should review, and revise if needed, "What's it All About? Ombudsman Program Primer for State Aging Directors and Executive Staff," as part of the preparation for meeting with the National Association of State Units on Aging.

Participants thought this was a very specific and helpful way to begin information exchange between NASOP and NASUA about systems advocacy.

2.11) NASOP should contact the National Association of Area Agencies on Aging to convene a joint workgroup.

Area Agencies on Aging (AAAs) have a responsibility to be advocates for older people, and AAAs help run most local ombudsman programs. AAAs need to be engaged fully in the effort for effective systems advocacy. Retreat participants identified AAAs and their national association as key players in many aspects of LTCOP systems advocacy. AAAs often work closely with zoning bodies, county commissioners, local media, and other local entities and could be very helpful to local ombudsmen.

Accountability:

2.12) NASOP should assert its influence on the Administration on Aging to fulfill its OAA responsibilities.

Retreat participants feel that given the enormity of OAA responsibilities and its many programs and stakeholders, it falls to NASOP to focus AoA on the LTCOP and to address the critical program issues. Participants recognized that given the lack of a full-time director of the Office of SLTCOP, the enormity of the jurisdiction of AoA, and the limited AoA staff and resources, it is appropriate for NASOP to be the voice of ombudsmen to AoA. NASOP must make sure that AoA is cognizant of the issues around systems advocacy, especially where the OAA mandate is not being fulfilled.

2.13) NASOP should review the findings and recommendations of the 1995 IoM report related to the ability of LTCOPs to carry out systems advocacy activities, and develop and implement a method for assessing the performance of state and local long-term care ombudsman programs.

Retreat participants thought it would be an appropriate role for NASOP to look back at the highly acclaimed IoM report and determine if it offers any further implications for improving systems advocacy.

Training and Qualifications for the LTCOP

Retreat Recommendations and Analysis

The appropriateness of those who serve as ombudsmen, in terms of their qualifications and the training they receive, has been a major focus and challenge for ombudsman programs throughout the LTCOP's history. Arguably, the role of an ombudsman in the long-term care setting is one of the most difficult positions imaginable. This is true for paid ombudsmen and even more so for volunteers. An ombudsman is expected to enter into a setting — the long-term care facility — as an outsider, and is there to accept and respond to complaints voiced by residents and those who voice them on their behalf; complaints are usually about or related to the care and services provided within the facility. The ombudsman may be met with an unpleasant, unfriendly and, on occasion, hostile and defensive reception by facility personnel, especially management.

When an ombudsman accepts a complaint, inherent within that complaint — depending upon its nature and severity — is the potential for serious consequences for the facility, such as complaint-triggered inspections, citations, civil monetary penalties, and even harsher sanctions including potential lawsuits. Potentially serious consequences for facility personnel can result from some complaint investigations including dismissals, sanctions related to their professional licenses, or worse. This is all to say that an ombudsman must be well trained to solve problems and pursue advocacy in various environments and under varying degrees of pressure.

Further, facility residents are typically very frail or disabled. They often suffer from Alzheimer's disease and other dementias or have other limitations in their ability to communicate, making informed consent and care directives very difficult. Consequently, the ombudsman requires specialized and sophisticated training on communication and caregiving for persons with mental health conditions and dementias.

Therefore, it is imperative that ombudsmen be right for the job. Recruitment strategies and techniques must identify appropriate candidates for the job — paid or volunteer — in terms of skills, values and temperament, so as not to waste personal or program time and resources. Turnover among ombudsmen, including volunteers, can be very high especially if ombudsmen are not appropriate for the roles or do not receive adequate training, supervision, and support. Particular attention must be paid to strategies to retain ombudsmen, especially volunteers, so as to minimize attrition within the ranks.

The skills needed to be an ombudsman are diverse and sophisticated, ranging from the ability to communicate effectively with providers and regulators, family members and representatives of community organizations, and, most importantly, residents. Communication skills must include the ability to interview and to effectively elicit facts and then to document the facts and information obtained. The core statutory role of the ombudsman is to investigate complaints, thus investigative skills, including those related

to evidence, are imperative in the role. The role is much more than to investigate complaints; it is to resolve complaints. Thus, the ombudsman must possess problem resolution skills, from developing problem-solving strategies to negotiating skills. Ombudsman managers must be able to provide solid supervision and direction to the ombudsmen under their jurisdiction to ensure effective and responsible ombudsman services in their states and communities.

Ombudsmen must be well trained. That includes ongoing training or continuing education, not only to refine and hone skills but also to learn new information and develop new skills. The long-term care field is dynamic, especially given the changing nature of the long-term care population (see separate discussion on this topic) and the long-term care field, including its oversight and financing.

Continued preparation for serving effectively as an ombudsman also requires feedback and evaluation. Individual ombudsmen, the programs within which they work, and the clients they represent, deserve to know what is working and what can be improved upon. Programs need the technical support and resources to engage in meaningful evaluation of their recruitment, training, and supervision of ombudsmen.

All of this has created on-going challenges for ombudsman programs throughout the country, from making proven strategies and techniques widely available to obtaining the resources to ensure adequate recruitment, training, supervision, and support of ombudsmen. The recommendations agreed to during the retreat address these challenges.

3.1) NASOP should articulate the values of the ombudsman program through a mission statement for the Long-Term Care Ombudsman Program, grounded in the Older Americans Act. Training should emanate from those values.

The breakout groups discussed the prospect of developing a national training program for state and local long-term care ombudsmen. In doing so, they realized that, over time, different approaches to their roles have evolved (e.g., advocacy vs. mediation). The programs also may have somewhat different goals (e.g., individual complaint resolution vs. systemic change), and emphasize different values (e.g., paternalistic vs. resident directed). Under these circumstances, it would be difficult to develop national training standards. The need for a mission statement became apparent to retreat participants to ensure that ombudsman programs function from a common core set of values and roles based on law. As one participant said, “training begins with values.” All ombudsmen, whether paid or volunteer, whether on the local, state, or national levels, would have a common understanding of the program’s mission, vision, and values. The OAA was considered the appropriate starting place for developing such a mission statement.

The recommendation was accepted in the conference meeting with only the addition of the phrase *for the long-term care ombudsman program*. It was accepted without change in the plenary session.

3.2) NASOP should promote and encourage state long-term care ombudsman programs to view training as a basic management function linked to other management processes, program policies, and procedures. NASOP should call upon all state long-term care ombudsman programs to review and evaluate their training programs to ensure compliance with the OAA and for internal consistency.

H. Wayne Nelson, the author of the retreat white paper on training and qualifications, points out that although NORC has developed "excellent" training materials, training programs vary widely across the nation. For example, preliminary training may range from 5 to 48 classroom hours. Nelson observed that on local, state, and national levels, concern exists about the inconsistency and inadequacy of LTCO training. The consequence of insufficient training is that LTCOP effectiveness can be compromised, resulting in lost opportunities for advocacy, unsolved or inadequately solved problems, unmet needs, and dissatisfied clients.

In addition, breakout group two pointed out that the state long-term care ombudsman programs should examine and evaluate their training programs to ensure consistency and effectiveness in their content and application.

This recommendation followed from the conference participants' discussion of national standards. Just as a mission statement is needed to clarify and reinforce the ombudsman program's vision and values, so too the LTCOP needs to know what training regimens (including curricula and methodologies) currently exist in order to move forward on developing nationwide training protocols. During the conference meeting, the participants combined two recommendations to create the final version of recommendation 3.2.

3.3) National standards for training representatives of the Office of the State Long-Term Care Ombudsman (individual designation or certification of representatives) should be developed by a task force of NASOP, the National Association of Local Long-Term Care Ombudsmen, the National Long-Term Care Ombudsman Resource Center, and others, as appropriate. The standards would address: (a) core competencies for basic certification training; (b) minimum number of hours for training prior to designation and for maintaining designation (on-going training); (c) content topics; and (d) methods. These standards need to be accessible to local ombudsmen via the Internet as well as other means.

The state long-term care ombudsman should direct the training. Topics for initial and continuing in-service training should include subjects such as:

- **Investigation and problem resolution skills**
- **Conflict of interest**
- **Confidentiality**
- **Access**
- **Autonomy**
- **Systems advocacy**
- **Reporting system**
- **Ombudsman values (including resident directed and resident centered)**
- **Ombudsman ethics**
- **Protocols for ombudsman work/roles**
- **OAA and the LTCOP**
- **Laws as tools, such as resident rights**
- **Resident direction: for care and also with ombudsman competency (Precedence Protocol for Advocacy)**
- **People resources and when ombudsmen need to contact them**
- **Mental health issues**
- **Alzheimer's and other dementias.**

Methods for training should include:

- **Looking at web-based tools such as manuals, questions and answers, core competencies, sections of content**
- **Facility visits, mentoring, and internships under the guidance of the LTCOP**
- **Application-based "Formal" evaluation before certification**
- **Conference calls on specific topics for on-going training**
- **Training conferences.**

Many of the retreat participants acknowledged the good work in the area of training by NORC. They conceded, however, that, in general, ombudsman training across the country needed improvement. There was a great deal of discussion and debate about the details of what those improvements should be. Some participants questioned the need for a national program, considering the differences between states and localities. The response was "an ombudsman is an ombudsman, regardless of state or locality." The issue of values arose, and the fact that values sometimes differ between programs. They agreed that the Precedence Protocol for Advocacy (PPA) should be a prominent part of the core competency curriculum. The author of the paper's position was that the PPA (*informed consent* first, *substituted judgment* second, and *beneficence* only as a last resort) should be a guiding principle in all ombudsman interactions regarding residents' rights.

The conference committee members agreed to rank the list of subjects considered for training topics by their order in the OAA provisions. Although the paper specified a training regimen, including format (lectures, role plays, etc.), number of hours of classroom work and home study, and other training aids, the breakout groups declined to be so specific in their recommendation. There was concern about being "over-prescriptive." Breakout group one wanted the task force to "recognize the complexities and grand scale of the subject." At the plenary session, the retreat participants added the phrase requiring Internet access to the training standards and they added "Alzheimer's disease" to the list of topics for continuing in-service training.

The evaluation phase is a key part of training. Only 11 states evaluate their ombudsmen for certification purposes. On-going training and performance appraisals also must be part of a complete management plan.

3.4) NASOP should work with the Administration on Aging, the National Association of Local Long-Term Care Ombudsmen, and the National Long-Term Care Ombudsman Resource Center to develop:

- **Role-appropriate selection criteria for ombudsmen;**
- **Management tools for ombudsman programs using volunteers, including recruitment and retention;**
- **Tools for understanding and minimizing attrition;**
- **Skills and tools for effective training including using new technologies. These products will be developed with an advisory group(s) of state and local ombudsmen.**

This recommendation reflects the retreat participants' agreement with the author on the subject of recruiting and training newly hired long-term care ombudsmen. The paper author points out that by spending extra time and effort upfront, the "payoff will be more competent and satisfied staff with decreased attrition down the road (Appendix VI, Nelson, p.7)." The paper identifies attributes that a screener would look for in an applicant (such as a sense of justice, which may be more important than empathy) and suggests resources for training effective interviewers. Breakout group one discussed interview

techniques for identifying a conflict avoider (for example, using an assessment tool called the Thomas-Killman conflict model), someone who is advocacy-oriented, etc. One group member suggested that an interviewer could ask "trick questions" during the screening, such as "how do you punish a patient when they do something wrong?"

The volunteer ombudsman is included in this recommendation. Volunteers can and do play a variety of roles in ombudsman programs, and they deserve appropriate recruitment and training both to enhance their performance outcomes and their own job satisfaction, as well as to contribute to overall program success. Volunteers and the issues of liability and provider relations were raised during the discussion. It was pointed out that some providers do not want to deal with volunteers because they want a trained, accountable, *paid* professional. For some providers, this is driven by the belief that volunteers may lack traditional motivations and incentives for not "stepping out of line" or for being too aggressive in their advocacy – e.g., wanting to keep their job, or pay raises. Of course, with appropriate selection, training, and supervision, a volunteer should be no different than any employee, whether they receive monetary compensation or not – i.e., an accountable, responsible, and valuable resource. It was broadly acknowledged at the retreat that the LTCOP needs resources to implement a successful volunteer program. It takes "money, commitment, and investment." The notion that volunteers come "free" of cost is absurd on its face, even more so if the expectation is that they are appropriately recruited and screened, trained, evaluated, and supervised; these are all management responsibilities that have program costs associated with each.

This recommendation also specifies the use of "new technologies." The breakout group participants felt that the LTCOP should take advantage of the growing number of opportunities for on-line learning, from virtual-lectures to topical chat rooms. The author points out that in using on-line forms of learning, "the learner's direct contact with the program need not be sacrificed, as long as in-service opportunities and continuing education courses are regularly scheduled (Appendix VI, Nelson, p.17)."

3.5) The National Long-Term Care Ombudsman Resource Center, working with NASOP, should expand the orientation for new state ombudsmen, covering the critical aspects of their role.

The Training paper offers a model for training new ombudsmen that covers the core content of the role. Breakout group one recommended that the paper be a resource for developing a tool for orienting new state ombudsmen to their role. In addition to an initial orientation, it points out that new information needs to be followed up with guidance, supervision, and feedback. For example, the new ombudsman may learn in the "classroom," but the theory must be applied at the facility and through interactions with residents, health care professionals, regulatory personnel, and others. In order to ensure that the program's values as well as the skills necessary for effective advocacy are instilled in the new ombudsman, on-going supervision or even mentoring should take place.

The participants considered the "critical aspects" to be included in the list of subjects listed under Training recommendation 3.3 (e.g., conflict of interest, confidentiality, systems advocacy, etc.). The other key point of this recommendation is that NORC should work with NASOP in the expansion of the orientation.

Also discussed in the paper was the idea of "facility rotation." This is an approach that programs embrace for at least two reasons: 1) so that an ombudsman doesn't get too "comfortable" in a particular facility and develop cozy relations with facility personnel; and 2) to ensure that more facilities have ombudsman coverage when there are not enough ombudsmen to cover the facilities within the jurisdiction. The retreat participants did not agree to a recommendation on this topic.

LTCOP Data and Information

Retreat Recommendations and Analysis

Data can be both the bane and blessing of long-term care ombudsman programs. Ombudsmen are often overwhelmed with their daily work – receiving and investigating complaints, raising funds and managing their programs, and working to improve the quality of care and life for long-term care facility residents, along with other tasks. Recording, analyzing, and managing data can be an immense chore for under-resourced and overworked advocates, especially when the data is thought of in terms of being done for bureaucratic or "bean-counting" purposes.

Yet, ombudsmen know that data and information, if done well, not only tell the story of how their program works or does not work, but also paint an accurate picture of the circumstances in which residents of nursing homes, assisted living, and other residential facilities find themselves. For example, several recent studies suggest that persons with dementia, such as Alzheimer's disease, are at increased risk of elder abuse. More data and better dissemination of the information could help ombudsmen provide the knowledgeable advocacy that people with Alzheimer's disease and their families deserve.

Retreat participants endeavored to reach agreement on how data and information related to the ombudsman program can be obtained, analyzed, and used in ways that are not cumbersome and are user-friendly; that are meaningful, useful and timely; that respect and protect confidentiality; and that can be reasonably paid for.

The conference committee members (all from the one breakout group) brought seven recommendations to the plenary session for the full body to consider. The recommendations focus on concerns for confidentiality of information, the usefulness of the data, and the technical integrity of the data and the computer system itself. Concerns related to conflicts of interest are also important. Other important issues include training on data systems, and the purchase and use of appropriate software. Language regarding confidentiality and conflicts of interest was added and approved at the plenary session for this topic.

4.1) NASOP should work with the Administration on Aging and others to plan a national reporting system that will incorporate disaggregated data that can be useful for comparisons, further study and research that supports advocacy, accountability, consumer information, and training through comparisons, further study, and research. The goal will be to implement the restructured system in five years. NASOP should appoint a workgroup to work with the National Long-Term Care Ombudsman Resource Center and the Administration on Aging to develop a plan and timeline, beginning in April 2002.

This recommendation acknowledges the importance of data and information for the ombudsman program, such as for systems advocacy and training. As an example, the

paper's author had pointed out how information about recurring problems in hygiene care and staffing had prompted an ombudsman program to press for the passage of legislation to increase the ratios of nursing assistants and of nurse supervision (Appendix VII, Kautz, p.5). Numbers tell the rational and objective story of what ombudsmen do and what long-term care facility residents face and experience. While specific case examples or anecdotal stories illustrate the story and provide emotional context, data provides a more complete picture, giving it scope and impact, making it more difficult for bureaucrats, the media, the public and policy-makers to dismiss individual cases of ombudsmen as isolated or "merely anecdotal."

Analysis of data can also assist long-term care ombudsmen in determining topics for training programs. If, as an example, ombudsman program data indicate increased complaints and cases related to matters involving disregard for or lack of bona fide advance directives or other expressions of personal choice by residents, this may suggest the need for training for ombudsmen on how to understand, investigate, and resolve complaints related to this matter. Moreover, it may suggest the need for training for long-term care facility personnel, as well as potential policy changes at the facility level or in public policy.

One of the key points about data collection and effective use of data has to do with disaggregated versus aggregated data. Recommendation 4.1 specifies disaggregated data because this type of data is the best kind for flexible use. Ombudsmen and other attendees agreed that it is easier to pull out, categorize, and analyze data that is disaggregated. The conferees said that the optimal data system would be one that is "seamless from local to state to national…" That is to say, data can be meaningful and useful locally but have similar meaning and usefulness at the state and national levels at the same time; data can be understood by a local ombudsman in a similar way that it is understood by the state ombudsman and by those "reading" it from a national perspective.

Breakout group members pointed out, however, that the cost of states' compliance with this national reporting system, including training costs, would be an obstacle to its successful implementation. While not addressed specifically during the retreat, this raises the issue of seeking additional federal funds that could be dedicated to data collection or serve as incentives to state expenditures on data collection, much like what has been done for states through Medicaid (e.g., enhanced matching rates for automation).

4.2) To promote consistency, integrity, and confidentiality of data, the Administration on Aging (AoA) should ensure that the state long-term care ombudsman has regular methods of auditing data. The AoA should provide training, technical assistance, and policy for such audits and on-going use of the National Ombudsman Reporting System. By the 2003 National Ombudsman Training, plans should be in place for training and NASOP should work with the National Long-Term Care Ombudsman Resource Center to plan regional training (AoA regions). NASOP should appoint a workgroup to work with the resource center and the Administration on Aging to develop a plan and timeline, beginning in April 2002.

This recommendation supports the importance of training for effective use of the National Ombudsman Reporting System (NORS). As the breakout group stated, "ongoing training is an essential part of making NORS accurate and useful."

Completeness, reliability of data, and ease of use are all aspects of data collection and data entry that must be integrated into the daily use of NORS by all ombudsmen, including volunteers. Auditing data is an important aspect of ensuring accuracy of data. The paper's author quoted one ombudsman who uses data frequently for legislative advocacy who said, "I've lost track of how many times a legislator has asked me: 'Are you confident of your data?'" (Appendix VII, Kautz, p.11). Moreover, retreat participants believed that technical assistance related to data and information on an on-going basis would help to ensure that systems remain contemporary and continue to reflect not only improvements in technology but changes in the substantive world of long-term care.

Participants of both the breakout group and the conference committee meeting spent a considerable amount of time discussing the significant variations among programs in their use of technology and data. The need for data verification and consistent standardized collection and recording processes were also discussed. Some states had made available the funds necessary to create systems to assure quality data collection and retrieval and others had not.

4.3) The Administration on Aging should begin immediately a two-step process to improve data collection capacity. The steps are:

a) AoA will establish baseline minimum standards for state program software.

b) AoA will publish and award grants to states to purchase necessary hardware and software to meet standards and assure data integrity and security.

Implementing NORS in 1995 was a major step toward standardizing ombudsman program data, and the IoM considered NORS a "laudable" achievement (Appendix VII, Kautz, p.7). However, it was pointed out that AoA should continue its work revising and refining the program's data collection capacity. At the conference committee meeting, the concept of *baseline minimum* standards was discussed and added to recommendation 4.3(a). In addition, the paper's author, Dr. Kautz, estimated that the cost per state of purchasing reporting software could be $16,000 - $19,785. The cost of purchasing computers, servers, etc., may be $40,000 - $50,000 for average states. LTCOPs need financial assistance to enable them to increase their computer capabilities to an acceptable level. Recommendation 4.4 also addresses this issue.

4.4) NASOP should work together with the National Long-Term Care Ombudsman Resource Center and the National Association of State Units on Aging in identifying resources for state ombudsmen to develop or purchase state-of-the-art computer systems and software that assist them in improving services and provide ease of data entry and data analysis. They should promote donations of computers by corporations and government without conflict of interest with the LTCOP.

This recommendation came out of the breakout group session without the second sentence. During the conference committee meeting, a second sentence was added which read, *"…identify a [n] NFP [not-for-profit] organization that would promote donations of computers."* The need for conflict of interest guidelines was discussed. Participants had concerns that accepting resources or computers from certain entities

could have the appearance of inappropriate relationships. In the plenary session, the second sentence was changed to specify direct donations of computers by corporations and governments, rather than through a not-for-profit organization, and the conflict of interest caveat was added. See recommendation 4.3 for information on the costs of computer systems.

4.5) States should be accountable for use of data systems to meet the various analytic and reporting requirements of the OAA. NASOP should work to sensitize states to the need to analyze and improve systems advocacy to improve the quality and services in facilities serving special needs populations (e.g., Alzheimer's disease).

During the breakout group session, participants discussed the need to help program staff and volunteers to appreciate the importance of data collection, entry, and analysis. They introduced the concept of using data to improve systems advocacy for Alzheimer's disease and other special needs populations. During the conference committee meeting and the plenary session, the wording of the last phrase was modified through several iterations from *"…to improve the quality for special needs populations (e.g., Alzheimer's disease)*" to *"…to improve the quality and services in facilities serving special needs populations (e.g., Alzheimer's disease)."*

4.6) NASOP should continue to develop standardized national outcome measures based on the work of the 2000-2002 Resource Center project.

Participants discussed the importance of outcomes measures and data. This data will help in program evaluation and training. They did not discuss changing the current outcomes development process.

4.7) NASOP and the National Association of Local Long-Term Care Ombudsmen should develop policies for providing complaint, inquiry, and other information to consumers and providers. These policies must provide for privacy and confidentiality concerns consistent with federal laws.

Discussion centered around ways to provide the public with more information on the way that the ombudsman program receives and responds to complaints. Although some participants had concerns about maintaining confidentiality, they felt it would serve the program's and the public's best interest to provide access to more information.

LTCOP Effectiveness

Retreat Recommendations and Analysis

What constitutes effectiveness by a long-term care ombudsman program varies with the needs and perspective of the stakeholder. For residents of long-term care facilities and those who voice complaints or raise concerns on behalf of residents, especially family members, an effective ombudsman is one who advocates for the resident and positively influences the outcome of a complaint or dispute. For a citizen advocacy group or senior services agency, an effective ombudsman might work for improvements in the quality of care in long-term care facilities or the long-term care services system. Policymakers and state and national governments may desire to note specific improvements in quality of care measures. Long-term care providers may believe an effective ombudsman is one who helps to resolve disputes with residents or their families without the involvement of regulatory bodies or the imposition of formal sanctions.

Robyn Grant, the author of the paper for the "Effectiveness" topic, points out that LTCOP effectiveness must first be viewed through the lens of the Older Americans Act. An analysis of the OAA language shows that the OAA "requires the program to ***advocate*** for residents' interests on both an individual and systems level, but it does not mandate that the program achieve resident quality of care and life (Appendix VIII, Grant, p.7)." Grant also points out that while improving the quality of life for residents is extremely important, having that as the program goal sets up unattainable expectations for the program. It was especially important to the retreat participants that this distinction be kept in mind while developing the recommendations for improving the effectiveness of the LTCOP.

The retreat participants also felt strongly that the ombudsman program's effectiveness is influenced to a very large degree by the program's independence. Ombudsman program independence relates to the program's ability to be free of conflicts of interest and to be able to carry out fully its advocacy activities without fear of unreasonable constraints, reprisal, or other organizational or relationship-related problems. During the plenary session the conferees stressed that the "linkages between independence and effectiveness need specific emphasis and reiteration. They seem to be complementary."

5.1) NASOP should work for the appointment of the Director of the Office of Long-Term Care Ombudsman Programs in the Administration on Aging. The director should fulfill the Older Americans Act mandate to investigate and resolve complaints about the Long-Term Care Ombudsman Program from citizens, consumers, and others.

This recommendation is a blend of a similar recommendation from the conference

session of the Independence group, a reflection of the overall importance of this recommendation. The retreat participants believe that the OAA provision adopted in the 1992 reauthorization is of immense importance to the LTCOP nationally. The provision in Title II of the OAA requiring that the Administration on Aging establish an Office of Long-Term Care Ombudsman Programs and that it be headed by a "Director" was established for several reasons. First, it is to provide a focal point and voice within the federal government for the states' long-term care ombudsman programs. This office is meant to reflect the specific and collective experiences of ombudsmen across the country especially in addressing the needs of facility residents, and to represent those needs with various federal agencies, including the Centers for Medicare & Medicaid Services, the Office of the Secretary of the Department of Health and Human Services, and others. Second, it is to serve as a focal point for the experience and needs of state LTCOPs within AoA. This would include monitoring the overall effectiveness of LTCOPs, and responding to complaints and concerns from individual states in that the LTCOP is perceived as not effective or not in compliance with OAA provisions, or in which complaints are raised about the LTCOP.

Subsequent to the retreat the Assistant Secretary for Aging appointed a respected senior AoA official as the Director of the Office of State LTCOPs. NASOP and the individual ombudsmen view this as a positive development. NASOP recognizes, however, that the official currently holding this position has many other responsibilities, thus his time spent on activities related to the position of Director of the Office of State LTCOPs is curtailed. The result is that the statutory array of roles and responsibilities delineated in the OAA for this position cannot be effectively implemented.

Breakout group one did not include this recommendation in its list. Breakout group two suggested that the Office of the LTCOP become "real." During the retreat there was discussion about including a requirement that the position be full-time and that additional language be adopted concerning the position's guidance and monitoring of the ombudsman program. The discussion made clear NASOP's belief that the authority and obligation for this role is already explicit in the law.

Following considerable discussion and several iterations during the conference meeting, this recommendation emerged as the number one recommendation with the addition that the "OAA be amended to resolve allegations and complaints about LTCOPs from citizens, consumers, and others." There was also considerable debate as to whether the OAA should be amended to require the AoA Office to "*investigate and* resolve" allegations and complaints, and whether "*state and local ombudsmen*" should be included in the list of complainants. While there was overall consensus that AoA must perform this role, there was agreement that it is not necessary to amend further the OAA with regard to this responsibility; that the law is sufficiently clear in its intent. During the plenary session, there was agreement that state and local ombudsmen are among those included in the "others" category of complainants to whom the AoA Office of LTCOPs is obligated to respond, and that this must be reflected in the final report from the retreat. This was also accompanied by discussion and agreement that AoA must be committed to confidentiality for complainants about the effectiveness of state LTCOPs.

Effectiveness breakout group two offered a recommendation that there be consideration of a "Residents' Rights Czar" at the federal level. Time constraints and other priority recommendations precluded this recommendation from being discussed in both the conference meeting and the plenary session.

5.2) In each state, the program shall be under the direction of one state long-term care ombudsman who is responsible for designating or certifying any local programs, supervising the work of program representatives, guiding program operations, training and designating or certifying ombudsman representatives, and participating in the hiring and firing of ombudsmen. Each state long-term care ombudsman program should be required to develop, implement, and enforce statewide policies for program operation.

This recommendation addresses the need for clear lines of authority and accountability. As provided for in the OAA, the state ombudsman should be the head of the program and direct all aspects of program operation. The OAA requires that the Office of the State Long-Term Care Ombudsman "shall be headed by an individual, to be known as the State Long-Term Care Ombudsman…" (Sec. 712(a)(2)) and that "The Ombudsman shall serve on a full-time basis" (Sec. 712(a)(3)). Both breakout groups included this recommendation in their priority recommendations and few changes were made to the language in the conference meeting. The conferees added language recommending that there shall be "one" state ombudsman (as opposed to more than one individual bearing this title at the same time), both because the OAA speaks to one individual in each state designated as "the State Long-Term Care Ombudsman," and for purposes of clear authority and accountability, recognizing that multiple individuals bearing the title as "the State Long-Term Care Ombudsman" increases the likelihood of confusion as to roles and authorities. The conferees also added the word "designating" to the recommendation agreeing that this is consistent with the OAA and more fully clarifies the authority of the state long-term care ombudsman. There was clear consensus during the plenary session with both additions.

Conferees and plenary participants also discussed the need to address, on a state-by-state basis, circumstances in which the state ombudsman lacks authority or a clear role in decisions related to the "hiring and firing" of local ombudsmen, especially when hiring and firing is done at the substate level, either by sponsoring area agencies on aging or other entities. There is clear recognition that it can create especially difficult circumstances for state ombudsmen when a local ombudsman is not appropriate for the role or is not performing effectively, or when the local hiring entity wants to terminate a local ombudsman who in the state ombudsman's judgment is performing effectively. State ombudsmen report experiences in which an AAA or other local hiring entity chooses to terminate an effective local ombudsman for cost reasons or because of her or his strong advocacy on behalf of residents or other local political reasons. These circumstances frequently result in the loss of seasoned and effective ombudsmen, trigger a lengthy learning period for replacement ombudsmen, and reduce at least for temporary periods effective response to residents' complaints. In addition, this personnel turnover requires additional costs for recruitment, training, and support for new ombudsmen.

Moreover, state ombudsmen report the frequent loss of local ombudsmen due to such reasons as inadequate wages, less than full-time positions and considerable inequities in working conditions among local programs, with the same outcomes as the loss of seasoned and effective ombudsman previously described. Participants stated that program effectiveness is enhanced when the state ombudsman has greater authority over the duties, working conditions, and benefits of local ombudsmen performing under the authority of the state's Office of the State Long-Term Care Ombudsman.

5.3) The state long-term care ombudsman and ombudsman program representatives should be housed in a setting where they are free of conflict of

interest and where independence is maximized. * The state long-term care ombudsman and ombudsman program representatives, at the direction of the state long-term care ombudsman, shall have the ability to advocate on behalf of residents in the following nonexclusive ways:

- **Represent the interests of residents before governmental agencies, legislative committees, individual legislators and other individuals, groups or entities where issues that affect residents are addressed;**
- **Communicate directly with directors of government entities, legislators, policy makers, and the media about issues affecting residents; and**
- **Provide uncensored public testimony.**

*** A minority of participants strongly believed that the LTCOP must be outside of government in order to fully represent residents.**

The topic of the organizational location of the state LTCOP was the subject of extensive discussion throughout the retreat especially in the context of both the topics of "Effectiveness" and "Independence." Although there is clear recognition that the current location of the LTCOP varies from state to state and that there may be significant weaknesses and shortcomings associated with certain organizational settings, the overarching sense of the group is that the most important goal for the LTCOP in terms of its effectiveness is to perform to the greatest extent possible the tasks listed in this recommendation. The consensus was that these roles were more important to focus upon than the minority view that the LTCOP must be fully independent in terms of its organizational setting; that effectiveness is best measured by the program's ability to fully represent and advance the interests and needs of facility residents. Nevertheless, the conferees did agree to include a note that some participants strongly believe that the LTCOP should be outside of government in order to represent residents fully.

The recommendation's use of the word "nonexclusive" indicates that despite the importance of the three referenced critical ombudsman tasks, they are not the only tasks ombudsmen perform; rather, they are major indicators of effective ombudsman services.

Discussion of this recommendation emphasized that the independence of the LTCOP, or the lack thereof, affects the ability of the ombudsman to fulfill her or his role. The placement of the program within, for example, a state agency, a not-for-profit social service agency, or a health care organization, likely influences the extent of its independence. In a 2001 report on effectiveness by Estes, et al., "more than one-half of state ombudsman programs reported that their organizational placement creates difficulties for service provision, with conflict of interest and lack of program autonomy identified most frequently as concerns (Appendix VIII, Grant, p.9)." The author of the Effectiveness paper also points out that the 1995 IoM report noted the "prevalence of conflicts of interest, both real and perceived, that arise from the structural location of many of the offices of the SLTCOP," a "disadvantage to the vulnerable client (Ibid, p.10)."

It is clear that a requirement that the long-term care ombudsman program be located in an independent, freestanding non-profit organization outside of government would need to be accomplished through an amendment to the OAA. If the program were starting from scratch this may be an important program requirement, but after three decades of LTCOP development with most state LTCOPs located in settings that do not

meet these criteria, it would be exceptionally difficult and disruptive to force a change in location in most states. Moreover, most participants believe requiring such a change would be unnecessary and perhaps counterproductive in many states. Participants recognized that there are state government-based LTCOPs that are notably effective and operating with considerable independence. Examples of such programs located in state units on aging include Oklahoma and Georgia, among others.

The conferees considered including a section from the Independence recommendation 1.4 in Effectiveness recommendation 5.3, which reads: "*to enhance independence and autonomy in representing residents, the state ombudsman and the local ombudsman program representative responsible for the operation of each local program (e.g., the LTCOP coordinator, the lead ombudsman) should be elevated to either be directly under the director of the agency or organization housing the program or be the director of the respective agency*."

While this section was not included as part of the final Effectiveness recommendation 5.3, there was general agreement among the retreat participants that the best situation for an ombudsman is to be organizationally located at very senior levels. For state ombudsmen, this would be reporting directly to the agency's head official. For local ombudsmen, this would either be a direct report to the local sponsoring organization's director or the organization's executive director. Participants believe there are several key program considerations that require that ombudsmen have the support, respect and authority that accompanies senior placement within any organization's hierarchy. These include:

- The scope and importance of authority required of ombudsmen under federal, and in many cases, state law;
- The gravity and potential sensitivity of matters handled by ombudsmen and the level of officials with whom ombudsmen must deal (e.g., regulators, trade association officials, corporate executives, law enforcement, and legislators); and
- The need for decision-making authority over use of resources, hiring and firing of ombudsman staff, and deployment of ombudsman staff (e.g., priority-setting as to which long-term care facilities will receive services).

5.4) The IoM-recommended minimum ratio of 1 paid designated ombudsman FTE to 2000 beds and 1 full-time staff ombudsman to 40 volunteers must be implemented in every state. The state long-term care ombudsman and SLTCO office staff should not be included in calculating this ratio (unless they personally investigate complaints in facilities). An ombudsman program staffing study is recommended to evaluate and recommend the staffing necessary to comply fully with the OAA requirements. Each local program should have at least one full-time paid ombudsman (not FTE). Additional paid program staff may be part-time, but shall have no duties conflicting with their role as ombudsmen.

This recommendation underscores the importance of adequate staffing for an effective and successful ombudsman program. The author of the Effectiveness paper pointed out that the work of the long-term care ombudsman has become increasingly complex over the years. Ombudsmen address complicated problems such as issues related to behavioral symptoms, transfers and discharges, and the ins and outs of managed care. A minimum number of paid, trained staff devoted to ombudsman

activities is critical to address and resolve issues effectively and promptly, and to ensure that all long-term care facility residents have equal access to ombudsman services.

The conferees discussed the role of part-time staff. While it is preferable to have full-time staff generally (for ease of training, management, and supervision, for example), part-time staff is helpful, especially if the resources are not available to support full-time staff. The conferees felt that the conflict of interest issue was important to reiterate in this recommendation thus they added the phrase *"but shall have no duties conflicting with their role as ombudsmen"* to the recommendation.

An early version of this recommendation included language calling for the OAA to be amended to require a staffing study, but this was changed to recommending that a staffing study be conducted — without relying upon a change in law to make such a study happen. The participants believe that such a study is not only important but is needed now and recognize that basing a study on a future amendment to the statute is unnecessary and possibly unwise. Given the vagaries of the legislative process such a study may never make it into the statute, may take years to occur, or be structured in a way that does not address the concerns of the retreat participants. Instead, the participants believe that such a study could be undertaken in the very near future through other means, such as from discretionary funding from AoA.

Both of the breakout groups included a recommendation that each state ombudsman program should have a volunteer program in place. However, such a recommendation did not emerge from the conference meeting among the top five recommendations. Due to time constraints, the full group in the plenary session did not take up all of the conference committee recommendations, including the recommendation concerning volunteer programs. Most retreat participants believe, however, that the role of volunteers in the ombudsman program is essential to providing individual ombudsman services to residents. Not only are complaint resolution rates higher in states with more active volunteers, but also in most states it is impossible to provide the routine presence of ombudsmen in long-term care facilities without volunteer ombudsmen. Moreover, even with generous funding, few states could ever ensure routine ombudsman visits to all covered facilities without a large corps of volunteers. Although this recommendation was not considered in the full session and as a result it cannot be said that all participants agree with it, it was offered by the Effectiveness conference committee among its top ten recommendations underscoring its importance.

5.5) The National Long-Term Care Ombudsman Resource Center should develop, in conjunction with NASOP and the National Association of Local Long-Term Care Ombudsmen, a tool to measure ombudsman program effectiveness, which shall utilize the IoM report, outcome measures, and recommendations from this conference. Each state and local ombudsman program should utilize this tool to evaluate its respective programs on an ongoing basis. State and local ombudsman programs should use the results of this evaluation to develop an action plan that includes specific, measurable, and scheduled objectives for each area of ombudsman program function required by the OAA.

Evaluating goals and priorities, measuring program effectiveness, monitoring where the program and its services have been and where it is going, are necessary steps for a program's future success. Indeed, this NASOP-Bader retreat is an example of such an

evaluation. For the ombudsman program, a critical component of such evaluation and self-examination is to ensure that local and state programs work together to develop measurement tools including both process and outcomes measures and to analyze program effectiveness, as specified in this recommendation. The author of the Effectiveness paper emphasizes that "the local program goals and priorities must stem from state goals and priorities so that the entire program is moving forward in a unified, integrated manner (Appendix VIII, Grant, p.18)."

In breakout group two, local ombudsmen said that funders want effectiveness and achievement outcomes that show "how/what have you done to change a life." Resolving complaints is not the fullest measure of what ombudsmen accomplish. A "resolved case" may not always be a good or complete measure of program effectiveness; there are many complaints that are "resolved" in the eyes of the complainant or others that may not have been handled in the best or fullest way possible. NASOP recognizes the importance of process measures as indicators of a program's effectiveness in addition to outcome measures. An example of a "process" measure might be timely investigation of complaints. While the timeliness of complaint investigation may not provide a measurement of successful outcomes it certainly bears upon program effectiveness (note Effectiveness recommendation 5.6). The implications of untimely response to complaints seem self-evident including: continued harm or other adverse consequences to the resident or others on untimely or delayed complaint investigation; diminished or lost evidence – a "colder trail;" and diminished respect for or reliance on the LTCOP. Even if the ombudsman is unable to provide a satisfactory resolution for the resident or complainant to a particular matter, the complainant may feel some satisfaction if she or he believes the ombudsman acted in a responsive and timely manner. No doubt an unsatisfactory outcome is exacerbated by delays in responding to a complaint.

5.6) Ombudsmen should prioritize and respond to complaints in the following manner:

COMPLAINT PRIORITIZATION AND RESPONSE TIME

PRIORITY LEVEL(From most urgent to least urgent)	TYPE OF COMPLAINT	RESPONSE TIME
Priority 1	§ Abuse or gross neglect and the ombudsman has reason to believe that a resident may be at risk § Actual or threatened transfer or discharge from a facility and the ombudsman has reason to believe the transfer or discharge will occur immediately § Action requiring a time-certain action	Within the next working day
Priority 2	Abuse or gross neglect and the ombudsman has no reason to believe that a resident is at risk	Within 3 working days
Priority 3	Actual or threatened transfer or discharge from a facility, and the ombudsman has no reason to believe that the transfer/discharge will occur immediately	Whichever occurs first: § 5 working days § last day of bed hold period if resident is hospitalized § last day for filing a transfer/ discharge appeal
Priority 4	Other types of complaints	Within 7 working days

This table was developed by the paper author and agreed to by the conferees with few changes.

Additional Recommendations

The Effectiveness conferees agreed upon four additional recommendations that due to time constraints were not taken up in the final plenary session. Therefore, it cannot be said that there was consensus among all the participants about the additional recommendations (breakout group one proposed all four, while breakout group two proposed the third and fourth ones). Nonetheless, since they were among the top ten agreed upon recommendations of the Effectiveness conference and because NASOP believes they are significant, they are included in this report.

- The state ombudsman shall have responsibility for making decisions about the use of the fiscal resources of the Office of State Long-Term Care Ombudsman and the OAA should be amended to require that the state ombudsman manage all fiscal resources related to the program. Local programs should be involved in fiscal management of their programs.

- The Office of the State Long-Term Care Ombudsman should directly employ, contract, or otherwise have a formal agreement with an attorney who has relevant experience and expertise and who is free of conflicts of interest.

- Each state ombudsman program should have a volunteer component in place including, but not limited to, volunteers who go to facilities to ensure that residents have direct access to ombudsman services.

- Ombudsman programs should organize staff and resources to maximize the potential that every resident has weekly access to an ombudsman program representative.

The Changing Long-Term Care Resident Population And Its Needs

Retreat Recommendations and Analysis

The overarching theme of this set of recommendations is the desire to ensure that all persons in need of long-term care services have access to ombudsman advocacy services. Specific populations with special needs are targeted, including residents with Alzheimer's disease and various underserved populations. Assisted living facilities residents are targeted for increased and improved advocacy and standards because of the vulnerability of this population and because ombudsman services are not as available in assisted living as they are in nursing facilities. Discussion also focused on funding for the ombudsman program, i.e., what the actual costs of the program would be if the residents of all nursing homes and other long-term care facilities were adequately served, as well as if the program were expanded or altered to respond better to contemporary long-term care facility residents. Finally, specific suggestions are made for NASOP to work collaboratively with other groups to increase public awareness about the ombudsman program and advocacy for special needs populations.

The author of the Changing Populations paper, Elma Holder, underscores the implications for the ombudsman program of the projected growth of the older population. The oldest old, those age 85 and over, for example, will double by the year 2020 to 7 million and double again by 2040 to 14 million (Appendix IX, Holder, p.4). It is among the oldest old population that long-term care needs will be the greatest thus the doubling of this cohort will place greatly increased demands upon long-term care services and therefore upon ombudsman programs. In addition, the needs of certain underserved (e.g., ethnic and cultural minorities) and special populations (e.g., disabled, mentally impaired) will increase as well, adding new demands and challenges for ombudsmen. For example, the paper author points out that about four million Americans have Alzheimer's disease, and the prevalence of the disease doubles every five years beyond the age of 65. The number of victims will grow to 14.3 million in the next 50 years, creating a challenge for both care providers and the ombudsmen monitoring the quality of their care.

The stark reality is that funding for the LTCOP remains "completely insufficient," as the 1995 IoM study found (Appendix IX, Holder, p.19). The scope of the ombudsman program initially was on nursing home residents. While board and care homes and other similar long-term care facilities were added to the LTCOP's scope and responsibility as an amendment to the OAA in 1981, the focus in terms of attention and resources has remained largely on the nursing home population. Now, other types of long-term care facilities, such as assisted living, as well as other forms of home and community-based care, are increasingly common and are expected to continue to grow

as options. Increased use of these long-term care options is not only due to resident and family preference but can be expected to receive increasing attention from cost-conscious policy-makers and providers. As an example, it is likely that expanded use of Medicaid waivers will continue and will increasingly be used for services in assisted living and other similar settings. Reports of quality of care problems are surfacing in assisted living and other facilities. Residents in all types of facility-based long-term care are in need of ombudsman advocacy services.

The recommendations for this Changing Populations topic reflect the current and projected demographics and conditions of the populations in need of long-term care services, and the current realities and projected needs of the ombudsman program. For example, recommendation 6.6 is consistent with the work of the nationally based Assisted Living Work Group, which was established after hearings by the Senate Special Committee on Aging aired consumers' problems in the nation's assisted living facilities. NASOP is a member of this work group.

The two breakout groups for this topic shared the conclusion, which formed the first recommendation, that persons receiving all forms of long-term care services deserve access to advocacy services and that such services should not be limited to those who reside in facility-based long-term care. Both groups also supported the need to determine the actual cost of the LTCOP if current federal mandates were fulfilled. Both groups also came up with recommendations for NASOP to implement a public awareness campaign and to adopt a strategy of working with other organizations, advocacy and disease-oriented, to further the goals of the ombudsman program.

Breakout group one recommended a five-year, five-state demonstration program of an optimal ombudsman program and proposed establishing an expert advisory panel to "examine and inform" the ombudsman program. Breakout group two recommended creating assisted living standards of care and a training program for ombudsmen in mental health conditions among their client population (e.g., dementia, depression, delirium).

The recommendations of the two groups were combined during the conference committee meeting. Group two's recommendation that "any expansion of the program into new arenas will not be undertaken unless the program is adequately funded" was incorporated into recommendation 6.2 and the wording modified to state that "any expansion…. must be accompanied by adequate resources…" Group two's language that, "NASOP will approach other health care organizations to motivate them to advocate for their communities/clients" became recommendation 6.7 calling for NASOP to "develop a plan to explore cooperative activities with national organizations that focus on persons with specific diseases."

Otherwise, there was little difference or disagreement between the two breakout groups and the full plenary session. The recommendations agreed to on a consensus basis by the retreat participants included:

6.1) NASOP should work to ensure that all persons in need of long-term care services have access to advocacy services.

6.2) NASOP will join with the National Association of Local Long-Term Care Ombudsmen, the National Long-Term Care Ombudsman Resource Center, and other allies to facilitate independent research to determine actual program costs if the current federal mandates were fulfilled. They will also

advocate that adequate resources for program success must accompany any adaptation or expansion of the program into new arenas.

6.3) NASOP will work with the Administration on Aging and the National Long-Term Care Ombudsman Resource Center to identify public and private funding sources for a five-year, five-state demonstration program to provide effective high quality "person-centered," independent, coordinated advocacy services to older persons in need of long-term care regardless of where they reside. An advisory panel of practitioners and scholars, whose work has demonstrated a command of the program's unique challenges, will oversee the evaluation of the demonstration.

6.4) NASOP will join with others to develop a public awareness campaign to heighten the visibility of the LTCOP and the people it serves. Further, NASOP will gather support for the program through coalition strategies with other senior advocacy organizations, direct care workers' organizations, and other public interest organizations.

6.5) NASOP will develop a position on access to long-term care ombudsmen in assisted living, a definition for assisted living, and national* standards for assisted living that are enforceable. (* "National" should not be mistaken for "federal.")

6.6) NASOP should continue its work with others on national standards of care for people in need of facility-based or residential assisted living.

6.7) NASOP will develop a plan to explore cooperative activities with national organizations that focus on persons with specific diseases. Activities will focus on advocacy to assist individuals and advocacy for systems change.

6.8) NASOP will promote, and develop as necessary, training programs for long-term care ombudsmen that focus on mental health conditions and conditions that affect decision-making capacity (e.g., Alzheimer's disease, dementia, depression, and delirium).

Afterword

Under the direction of the president of the organization, the National Association of State Ombudsman Programs has met a number of times since the completion of this retreat in the winter of 2002. Individual members and groupings of members have been assigned to explore the options available to the association to pursue activities that will advance the concepts contained within the various recommendations emanating from the retreat. Collectively the organization recognizes that much work is needed to support and shore up individual state programs in order for all member states to carry out the mandates embodied within the Older Americans Act.

As an affiliation of peers, NASOP is well positioned to provide quality training and technical assistance to each of its members. The recommendations contained in this report are already serving as the basis for revising much of this activity. Existing approaches are being evaluated and measured against specific needs that have been articulated by this retreat's report.

Management of the volumes of data that the nation's ombudsman programs generate must be harnessed to positively guide the development of national and state long-term care laws and policies. NASOP is prepared to do just that.

Long-term care is evolving from its very early beginnings of "rest homes" into a much more complex array of services ranging from highly technical supports to the most simple offerings to maximize the independence of frail, older persons. To meet the changing needs of these consumers, ombudsman programs must re-evaluate their focus and continually measure effectiveness in order to truly protect citizens' rights within this system. NASOP accepts and embraces this challenge.

NASOP also knows full well that in order for its members to be successful in this important work, additional resources will be needed to match the increasing demand for services from a widening audience. The organization is committed to that effort.

Early in 2002, five committees were constituted specifically to take up the major recommendations contained within this report. Each has been meeting to identify the necessary steps to be taken by NASOP and/or its affiliated organizations to implement fully the requirements of the Older Americans Act.

Specific committee activities to date include:

Training. A survey of all member states to determine training practices and curriculum of paid and volunteer ombudsmen has been conducted. The committee has recommended to NASOP that the National Long-Term Care Ombudsman Resource Center (NORC) dedicate part of its work-plan for the next grant cycle to include development of minimum training standards, evaluation instruments, and core competencies. The committee, along with the National Association of Local Long-Term Care Ombudsmen, will work with NORC to develop a voluntary certification of

ombudsmen, and create a model screening instrument for prospective ombudsmen. The committee will also lead NASOP's efforts to develop or identify training materials for special populations, i.e., Alzheimer's disease, etc.

Effectiveness. This committee is tackling structural issues and important relational concerns with other organizations to maximize the effectiveness of each of the state ombudsman programs. Of top priority is raising the visibility of the program within the Administration on Aging and to enhance the independent action of all state ombudsmen. Dialogue with the National Association of State Units on Aging will focus on improved understanding of the unique role of the ombudsman and its basic mandate. The committee is examining structures that will improve the independent operations of local ombudsman programs as well, which will draw upon discussions with the National Association of Area Agencies on Aging. On a separate track, the committee is working with the NORC to create a tool to objectively measure the effectiveness of each ombudsman program, including the ability of the program to advocate effectively for changing populations in long-term care facilities.

Data. This committee is undertaking a review of the status of the technological condition of ombudsman programs around the country to determine what basic computer supports, including hardware and software, will be needed to actualize the value of a sophisticated databank. Ultimately the goal is to create consistent collection of program data, leading to analysis that is defensible in both the public and private arena. These sources of data would form the basis for advocacy efforts within larger systems both at the state and national levels.

Systems Advocacy. To fully achieve the congressional mandate for the ombudsman concept, each program must be positioned to go well beyond individual complaint resolutions and into the sphere of altering public policy that improves the well-being of the long-term care consumer. This committee is drawing upon the findings of other NASOP committees with a goal of providing the tools each state program will need in order to speak openly and effectively about the unacceptable conditions found in many sectors of the long-term care system. The chair of this committee has begun working with the NORC to train new state ombudsmen in systems advocacy.

Appropriations. This long-standing committee of NASOP will continue its work with Congress, educating legislators and their staffs of the needs faced by ombudsman programs around the country. The federal government remains a critically important source of funding. Increased funds will be needed to support programs as they answer the call to expand their advocacy services beyond the more traditional nursing home. The committee will continue to raise these issues with members of Congress. In addition the committee is preparing to find other resources to match specific projects that are prioritized by the NASOP membership.

NASOP is prepared to take on a pivotal role among other players on the national scene to design a long-term care system that is fair and equitable and that honors the very basic dignity of each person who enters that system.

In conclusion, this is the beginning of a process for NASOP, not the end. We thank all of those individuals who helped to make the retreat a success for NASOP and for getting us started on the next stage of our journey on behalf of long-term care residents.

For more information contact:

NASOP
2007 Trail Wood Circle
Midland, MI 48642-3787
Phone: 989-631-3817